

## SURVEYS OF THE AMERICAN DEAF POPULATION: A CRITICAL REVIEW

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*This is a critical review of surveys conducted on the American deaf population since 1990. There is no agreement among the surveys on the number of deaf and hard of hearing individuals in the US. This behooves us to study the question: Why the lack of agreement in estimates and prevalence rates of the American general deaf and the deaf child population across the surveys? Prior studies explained the discrepancies in terms of sampling and probability errors, different survey methodologies, federal mandates, changing medical conditions and fluctuations in prevalence rates. It is proposed here that the estimates are delimited by the mandates, purposes, survey questions, definitions of population cohorts and survey methodologies devised by the surveying institutions*

Since 1990 there are different surveying institutions that conducted surveys of the American deaf population, both the general deaf and the deaf child population. They provided definitions of individuals with deafness, estimates and prevalence rates of the total deaf population. Below are two sets of tables showing the cohorts, estimates and prevalence rates for the deaf population in the US since 1990 from different surveys. One set of tables, Tables 1 to 7, covers the adult deaf population and another set of tables, Tables 8 and 9, covers the child deaf population.

*Adult Surveys: Population Estimates and Prevalence Rates by Demographic Surveys*

**Table 1**  
**Decennial Census—Content Reinterview Survey**

SURVEY DATES	DEFINITIONS	POPULATION SIZE	PREVALENCE RATES
1990 <sup>1</sup>  Covered persons aged 16 and over	Difficulty in hearing what is said in normal conversation	10879622	1 per 25 = 4% of general population  5.82% of total disabled population
	Unable to hear what is said in normal conversation	917605	1 per 250 = 0.4% of general population  0.49% of total disabled population

Source:  
1-US Bureau of the Census. (2002).

The tables show that different surveys produced different population estimates and prevalence rates. When population estimates for a particular year are compared across surveys, no similarities are seen. For the year of 1991 SIPP counted almost 11 million individuals who have hearing difficulties and NHIS counted about 21 million individuals with hearing impairments. In addition, the surveys do not cover individuals of the same age range. For example, the 1997 SIPP counted about 8.3 million individuals with all ranges of hearing difficulties for six year olds and over and the 1997 NHIS counted close to 35 million individuals aged 18 years and over with hearing trouble. In addition, there are two surveying institutions that counted deaf children and they do not agree on estimates for the same year. The discrepancies between the Child Counts and the Annual Surveys estimates are also found for other years. For the academic year of 2000-2001, for example, the Child Counts counted about 71,000 deaf children and the Annual Survey counted about 43,000 children. For 2003-2004 the Child Counts counted 72,000 children while the Annual Surveys counted about 38,000.

*Table 2*  
**Survey of Income and Program Participation**

SURVEY DATES	DEFINITIONS	POPULATION SIZE	PREVALENCE RATES
1991-1992 <sup>1</sup> Covered persons aged 15 and over	Difficulty hearing normal conversation	10928000	5.6% of general population aged 15 and over
	Is unable to hear normal conversation	924000	0.5% of general population aged 15 and over
1994-1995 <sup>2</sup> Covered persons aged 6 and over	Difficulty hearing normal conversation	10110000	4.3% of general population aged 6 and over
	Unable to hear normal conversation	977000	0.4% of general population aged 6 and over
1996-1997 <sup>3</sup>	Had difficulty hearing conversation Ages 6-14	234000	0.7% of general population aged 6-14
	Not severe difficulty hearing conversation Ages 6-14	177000	0.5% of general population aged 6-14
	Had severe difficulty hearing normal conversation Ages 6-14	57000	0.2% of general population aged 6-14
	Had difficulty hearing conversation Ages 15 and over	7966000	3.8% of general population aged 15 years and over
	Not severe difficulty hearing conversation Ages 15 and over	7134000	3.4% of general population aged 15 years and over
	Had difficulty hearing normal conversation Ages 15 and over	832000	0.4% of general population aged 15 years and over
2001-2002 <sup>4</sup>	Had difficulty hearing conversation Ages 6-14	203000	0.5% of general population aged 6-14
	Not severe difficulty hearing conversation Ages 6-14	164000	0.4% of general population aged 6-14
	Had severe difficulty hearing normal conversation Ages 6-14	39000	0.1% of general population aged 6-14
	Had difficulty hearing conversation Ages 15 and over	7830000	3.5% of general population aged 15 years and over
	Not severe difficulty hearing conversation Ages 15 and over	6859000	3.1% of general population aged 15 years and over
	Had severe difficulty hearing normal conversation Ages 15 and over	972000	0.4% of general population aged 15 years and over

Sources:

1-McNeil, J.M. (1994).

2-McNeil, J.M. (1997).

3-McNeil, J.M. (2001).

4- Steinmetz, E. (2004).

**Table 3**  
**National Health Interview Survey**

SURVEY DATES	DEFINITIONS	POPULATION SIZE	PREVALENCE RATES
1991 <sup>1</sup>	Hearing impairments	20295000	8.6% of general population
Covered all persons	Deafness	1350000	0.57% of general population
1993 <sup>2</sup>	Hearing impairments	24160000	N/A
Covered all persons			
1994 <sup>3</sup>	Hearing impairments	22400000	N/A
Covered all persons			
1996 <sup>4</sup>	Hearing impairments	N/A	83.4% per 1,000 persons in the general population
Covered all persons			
1997 <sup>5</sup>	A little trouble hearing	28789000	14.8% of general population aged 18 years and over
Covered persons aged 18 and over	A lot of trouble hearing or deaf	5963000	3.1% of general population aged 18 years and over
2001 <sup>6</sup>	A little trouble hearing	28411000	14.0% of general population aged 18 years and over
Covered persons aged 18 and over	A lot of trouble hearing or deaf	6998000	3.4% of general population aged 18 years and over
2003 <sup>7</sup>	Hearing trouble	32533000	15% of general population aged 18 years and over
Covered persons aged 18 and over			
2004 <sup>8</sup>	Hearing trouble	35135000	16.3% of general population aged 18 years and over
Covered persons aged 18 and over			
2006 <sup>9</sup>	Hearing trouble	37215000	16.9% of general population aged 18 years and over
Covered persons aged 18 and over			

Sources:

- 1-Reis, P.W. (1994).
- 2-Benson, V., & Marano, M.A. (1995).
- 3-Adams, P.F., & Marano, M.A (1995)
- 4-Adams, R.F., G.E. Hendershot, & Marano, M.A (1999).
- 5-Blackwell, D.L., Collins, J.G., & Coles, R. (2002).
- 6- Lucas, J.W., Schiller, J.S., & Benson, V. (2004).
- 7-Lethbridge-Cejku, M., & Vickerie, J. (2005).
- 8- Lethbridge-Cejku M, Rose D, & Vickerie J. (2006).
- 9- Pleis JR, Lethbridge-Çejku M. (2007).

**Table 4**  
**National Postsecondary Student Aid Survey (NPSAS)**

SURVEY DATES	DEFINITIONS	POPULATION SIZE	PREVALENCE RATES
1989-1990 <sup>1</sup>	Hearing impaired or deaf UG <sup>6</sup>	N/A	1.6% of UG students
	Hearing impaired or deaf GIP <sup>7</sup>	N/A	1.2% of GIP students
1992-1993 <sup>2</sup>	Hearing impaired or deaf UG	N/A	1% of UG students
	Hearing impaired or deaf GIP	N/A	0.8% of GIP students
1995-1996 <sup>3</sup>	Hearing impaired or deaf UG	N/A	0.7% of UG students
	Hearing impaired or deaf GIP	N/A	0.5% of GIP students
1999-2000 <sup>4</sup>	Hearing impaired or deaf UG	N/A	0.7% of UG students
	Hearing impaired or deaf GIP	N/A	0.5% of GIP students
2003-2004 <sup>5</sup>	Services needed: sign language or oral interpreters	N/A	0.1% of GIP students

## Sources:

1-U.S Department of Education, National Center for Education Statistics. (1991)

2-U.S Department of Education, National Center for Education Statistics. (1994)

3-U.S Department of Education, National Center for Education Statistics. (1997).

4-U.S Department of Education, National Center for Education Statistics. (2001).

5-U.S Department of Education, National Center for Education Statistics. (2005).

## Notes:

6-UG = undergraduates

7-GIP = graduates and first-professional

**Table 5**  
**Beginning Postsecondary Students Longitudinal Study (BPS)**

SURVEY DATES	DEFINITIONS	POPULATION SIZE	PREVALENCE RATES
1989-1990 <sup>1</sup>	Hearing impairment or deaf	N/A	19.8% of beginning postsecondary students with disabilities (based on NPSAS:90)
1992-1993 <sup>2</sup>	Hearing impairment or deaf	N/A	15.3% of beginning postsecondary students with disabilities (based on NPSAS:90)
1993-1994 <sup>3</sup>	Hearing impaired postsecondary students	N/A	0.3 % of postsecondary students (based on NPSAS:96)
1995-1996 <sup>4</sup>	Hearing impaired postsecondary students	N/A	0.6% of postsecondary students (based on NPSAS:96)
2003-2004 <sup>5</sup>	Service needed: Sign language or oral interpreters	N/A	0.1% in 4-year institutions of higher education

**Sources**

1-U.S Department of Education, National Center for Education Statistics. (1995a).

2-U.S Department of Education, National Center for Education Statistics. (1995b).

3-U.S Department of Education, National Center for Education Statistics. (1995c).

4-U.S Department of Education, National Center for Education Statistics. (2002a).

5-U.S Department of Education, National Center for Education Statistics. (2007).

**Table 6**  
**Baccalaureate and Beyond Longitudinal Study (B&B)**

SURVEY DATES	DEFINITIONS	POPULATION SIZE	PREVALENCE RATES
1993-1994 <sup>1</sup>	Service needed: Sign language or oral interpreters	N/A	0.6% of postsecondary students (based on NPSAS:93)
1999-2000 <sup>2</sup>	Service needed: Sign language or oral interpreters	N/A	0.5% of postsecondary students (based on NPSAS:2000)

Sources:

1-U.S Department of Education, National Center for Education Statistics. (1998).

2-U.S Department of Education, National Center for Education Statistics. (2002b).

**Table 7**  
**Survey on Deaf and Hard of Hearing Postsecondary Students**

SURVEY DATES	DEFINITIONS	POPULATION SIZE	PREVALENCE RATES
1989-1990 <sup>1</sup>	Hard of hearing postsecondary students	5950	N/A
	Deaf postsecondary students	3610	N/A
	Did not distinguish between deaf and hard of hearing	7470	N/A
1990-1991 <sup>2</sup>	Hard of hearing postsecondary students	6740	N/A
	Deaf postsecondary students	3750	N/A
	Did not distinguish between deaf and hard of hearing	7860	N/A
1991-1992 <sup>3</sup>	Hard of hearing postsecondary students	7500	N/A
	Deaf postsecondary students	4220	N/A
	Did not distinguish between deaf and hard of hearing	7730	N/A
1992-1993 <sup>4</sup>	Hard of hearing postsecondary students	7770	N/A
	Deaf postsecondary students	4520	N/A
	Did not distinguish between deaf and hard of hearing	7750	N/A

Sources:

1- Lewis, L., & Farris, E. (1994).

2- Lewis, L., & Farris, E. (1994).

3- Lewis, L., & Farris, E. (1994).

4- Lewis, L., & Farris, E. (1994).

*Child Surveys: Population Estimates and Prevalence Rates by Demographic Surveys***Table 8**  
*Child Counts*

SURVEY DATES	DEFINITIONS	POPULATION SIZE	PREVALENCE RATES
1990-1991 <sup>1</sup>	Children with hearing impairments= Children aged 6 to 21 years old who are diagnosed as deaf and hard of hearing and who receive IEP.	60145	1.2% of disabled student population
1991-1992 <sup>2</sup>		60727	1.2% of disabled student population
1992-1993 <sup>3</sup>		60616	1.2% of disabled student population
1993-1994 <sup>4</sup>		64665	1.2% of disabled student population
1994-1995 <sup>5</sup>		65204	1.2% of disabled student population
1995-1996 <sup>6</sup>	Children with hearing impairments= Children aged 6 to 21 years old who are diagnosed as deaf and hard of hearing and who receive IEP.	68039	1.2% of disabled student population
1996-1997 <sup>7</sup>		68773	1.2% of disabled student population
1997-1998 <sup>8</sup>		69783	1.2% of disabled student population
1998-1999 <sup>9</sup>		70786	1.2% of disabled student population
1999-2000 <sup>10</sup>	Children aged 3 to 5 years old	7751	1.3% of disabled student population
	Children aged 6 to 21 years old	70810	1.1% of disabled student population
2000-2001 <sup>11</sup>	Children aged 3 to 5 years old	7240	1.2% of disabled student population
	Children aged 6 to 21 years old	71225	1.2% of disabled student population
2001-2002 <sup>12</sup>	Children aged 3 to 5 years old	7237	1.1% of disabled student population
	Children aged 6 to 21 years old	71962	1.2% of disabled student population
2002-2003 <sup>13</sup>	Children aged 3 to 5 years old	7496	1.1% of disabled student population
	Children aged 6 to 21 years old	72023	1.2% of disabled student population
2003-2004 <sup>14</sup>	Children aged 3 to 5 years old	7824	1.1% of disabled student population
	Children aged 6 to 21 years old	72626	1.2% of disabled student population
2004-2005 <sup>15</sup>	Children aged 3 to 5 years old	7846	1.1% of disabled student population
	Children aged 6 to 21 years old	72387	1.2% of disabled student population
2005-2006 <sup>16</sup>	Children aged 3 to 5 years old	8208	1.1% of disabled student population
	Children aged 6 to 21 years old	72559	1.2% of disabled student population

Sources:

1-16 Office of Special Education Programs. (1992-2007).

**Table 9**  
**Annual Survey of Deaf and Hard of Hearing Children**

SURVEY DATES	DEFINITIONS	POPULATION SIZE
1989-1990 <sup>1</sup>	Hearing impaired children Receiving primary or secondary special educational services	46666
1991-1992 <sup>2</sup>		47822
1993-1994 <sup>4</sup>		47014
1994-1995 <sup>3</sup>	All deaf and hard of hearing children receiving special educational services	47616
1996-1997 <sup>4</sup>	Deaf children in all schools	50629
	Deaf who received special education services	43267
1999-2000 <sup>5</sup>	Deaf who received special education services	43861
2000-2001 <sup>6</sup>	Deaf who received special education services	43416
2001-2002 <sup>7</sup>	Deaf who received special education services	42361
2002-2003 <sup>8</sup>	Deaf who received special education services	39493
2003-2004 <sup>9</sup>	Deaf who received special education services	38177
2004-2005 <sup>10</sup>	Deaf who received special education services	37500
2006-2007 <sup>11</sup>	Deaf who received special education services	37352

No information is available for the year of 2005-2006.

Sources:

- 1- Schildroth, A.N., & S.A. Hotto. (1991).
- 2- Schildroth, A.N., & S.A. Hotto. (1993).
- 3- Schildroth, A.N., & S.A. Hotto. (1996).
- 4- Holden-Pitt, L., & J.A. Diaz. (1998).
- 5- Gallaudet Research Institute. (2001).
- 6- Gallaudet Research Institute. (2002).
- 7- Gallaudet Research Institute. (2003a).
- 8- Gallaudet Research Institute. (2003b).
- 9- Gallaudet Research Institute. (2005a).
- 10- Gallaudet Research Institute. (2005b).
- 11- Gallaudet Research Institute. (2006).

As seen in the tables above, most surveys included prevalence rates that were calculated as the number of individuals with deafness divided by the total general population, both deaf and hearing. This suggests that the surveys see the estimates to represent the total deaf population in the US. However, there are differences across surveys in prevalence rates and the age groups they covered for the same year. In the 1991 SIPP the prevalence rate was 6.14% of the general population of 15 year old and over and in the 1991 NHIS it was 9.17% of the total general population. In the 1997 SIPP the rate was 4.5% of the population of 6 year old and over and in the 1997 NHIS it was 18% of the population of 18 year old and over. Furthermore, as indicated in the table, the prevalence rates in Child Counts and Annual Surveys are not comparable. The prevalence rates in Child Counts are calculated as the number of children with deafness, divided by the total population of children with disabilities. The Annual Surveys did not provide the prevalence rates.

The tables behoove us to study the question: Why the divergences in estimates and prevalence rates of the American general deaf and the deaf child population across the surveys?

Various demographers offered several explanations for the variations in population estimates across surveying institutions. Demographers who studied American deaf population surveys such as Reis (1994) and Schein (1996) explained that the population estimates have in-built sampling and probability errors. Sampling errors occur as a result of misclassifications of individuals into population cohorts whereby some are counted and others are overlooked. Probability errors are caused by miscalculations in population estimates. Schein (1996) added that sampling errors and fluctuations in prevalence rates in the US over time caused variations in population estimates. Schildroth and Hotto (1996) and Holden-Pitt and Diaz (1998) saw that population estimates are impacted by changing medical conditions and federal mandates on education that affected the size and distribution of children in schools and programs for the deaf. One demographer, Reis (1994), proposed that different survey methodologies and population cohorts create variations in estimates across different surveys in the US. For these demographers sampling and probability errors, different survey methodologies, federal mandates, changing medical conditions and fluctuations in prevalence rates over a number of years are the causes for the differences in population estimates across surveys.

However, an investigation of survey reports reveals that the reasons for the differences in population estimates across surveys conducted by different surveying institutions go beyond those that are proposed in the demography literature. In the ensuing discussion this researcher proposes an alternative explanation for the differences in population estimates. In order to understand divergences in population estimates produced by different surveying institutions, this researcher utilizes a critical demography model.

A recent paradigm in population studies, critical demography examines the relationship between population estimates and the social systems of the surveying institutions (Horton, 1999). Scherper-Hughes (1997) and (Horton, 1999) argued that the agendas, or policies and practices, of the surveying institutions conceptualize a population cohort, structure the questions asked, enumerate individuals into certain cohorts, often to the exclusion of others, and shape the findings. Critical demography also holds that population estimates are delimited to certain population cohorts that respond to survey questions that are constructed in accordance with the agendas of the surveying institutions (Hammel & Howell, 1987; Demeny, 1988; Greenhalgh, 1996; Scherper-Hughes, 1997; Riley, 1997, 1999; Black, Gates, Sanders, & Taylor, 2000). In addition, the surveys are not initiated without purpose and funding by individuals, organizations and constituencies that establish the agenda, design and conduct the surveys, and use survey data to assess and legitimize their agendas, programs and services. In order to understand the lack of agreement in population estimates across surveys, one needs to understand that the different estimates are the result of the different needs and purposes, survey questions and methodologies and definitions of population cohorts of the surveying institutions.

In this review of surveys this researcher argues that each survey of the American deaf population has different purposes, surveying methodologies, definitions of deafness and population cohorts that effect on population estimates and prevalence rates, and that the different purposes, methodologies and definitions of population cohorts across surveys create for differences in population estimates and rates. The purpose of this review is to examine the ways in which the mandates and purposes of the surveying institutions determine the way survey questions are framed, cohort definitions are constructed, methods of enumeration are formulated and estimates are calculated. This researcher will show how different surveying institutions created different estimates because they have different mandates, agendas, survey methods and definitions of population cohorts.

### **A Critical Review of Surveys**

#### *Survey mandates*

All surveys were mandated and funded by the US Congress. Since the mandates for all surveys originated from one authorizing source, it is anticipated that all surveys share the same mandates, survey methodologies, population cohorts and population estimates. However, it is not so. While all surveys, with the exception of the Annual Survey of Deaf and Hard of Hearing Children, were mandated and funded by the US Congress, not one surveying institution compiled demographic figures for the entire American deaf population. Each survey has a different history, was compiled by different and competing constellations of federal, public and private service agencies and was mandated by different acts of Congress. Congress provided funding and support to the US Department of Commerce, the US Department of Health and Human Services, the US Department of Education, and Gallaudet University to conduct the surveys. The US Department of Commerce, through its Office of the Bureau of the Census, conducted two surveys of the general American deaf population. They are



the Content Reinterview Survey (CRS) and the Survey of Income and Program Participation (SIPP). An Act of Congress established the annual census in the 19<sup>th</sup> century. The SIPP was mandated in Title 13, USC Section 182 of ADA in 1990. The Department of Health and Human Services performed the National Health Interview Survey (NHIS). The NHIS is a result of congressional reorganization of the Census Bureau and the creation of the Center of Disease Control in mid-1950.

The US Department of Education conducted several surveys through its centers, programs and offices. The Postsecondary Education Program of the Center for Education Statistics (NCES) of the US Department of Education performed several surveys on adults attending postsecondary education. The NCES surveys that contain information on deafness are the National Postsecondary Student Aid Survey (NPSAS), the Beginning Postsecondary Students Survey (BPS), and the Baccalaureate and Beyond Longitudinal Survey (B&B). what is this? (This is the acronym used to refer to the survey, e.g. B&B: 97.) The NCES is established by congressional action, with NPSAS formed since mid-1980s, the BPS is mandated by PL103-382, and the B&B followed the NPSAS survey of 1990. The Office of Special Education and Rehabilitation Services (OSERS) of the US Department of Education conducted three surveys of American deaf student population. Its Office of Special Education Programs (OSEP) compiled the Survey on Deaf and Hard of Hearing Students in Postsecondary Education and the annual Child Counts. The Survey on Deaf and Hard of Hearing Students in Postsecondary Education was requested by OSEP in 1993. The Child Counts Survey was mandated in IDEA of 1990, PL101-476, which is a result of a succession of laws promoting special education starting from PL89-313 in 1968, to PL94-142 for ECHA in 1974, and PL99-457 in the EHA in 1986. The OSERS, in contract with the Research Institute of Gallaudet University, also performed another annual survey, the Annual Survey of Deaf and Hard of Hearing Children. A contract between the old Bureau of the Education of the Handicapped of the old US Department of Health, Education, and Welfare and Gallaudet University in 1968 initiated the Annual Surveys.

#### *Needs and purposes of surveying institutions*

The surveying institutions differed in the congressional mandates for conducting their surveys of the deaf population. The different mandates for the surveys arose because of different needs and functions of the surveying institutions. The different functions and needs of the surveying institutions have generated different purposes for the surveys. The surveying institutions conduct surveys largely for the purpose of gathering information on the appropriation and effectiveness of the missions, programs and services of the surveying institutions. Each survey focuses on different aspects of deafness that are integral to the missions, programs and services of the surveying institutions, which reflect different juxtapositions between deafness and society.

The US Department of Commerce has several functions. One is to monitor demographic trends in the US population. It needs information on the characteristics, size, dispersion and trends in the number of individuals who experience hearing difficulties. It conducts CRS surveys for the purpose of gathering information on the American deaf population aged 16 and over in their abilities to use hearing in order to participate in society, to perform societal tasks, and to live independently (US Census Bureau, 1997). With this information the Commerce Department makes policy and appropriations for public and private programs and services for individuals with hearing difficulties (US Census Bureau, 1997).

Another function of the Commerce Department is to monitor labor and employment patterns in the general deaf and hard of hearing population. It needs information on the employment of deaf people, and conducts SIPP surveys for the purpose of collecting information on persons and households with hearing disability conditions and its relationship with employment, self-help, and participation in labor force and in federal and state government subsistence programs (McNeil, 1994, 1997, 2000, 2001). With this information the Commerce Department identifies gaps in program needs and program participation, make appropriations of funds, and establish programs and services (McNeil, 1994, 1997, 2000, 2001).

The US Department of Health and Human Services has the function to monitor the health and general well being of deaf people. It needs information on the health and general well being of deaf people, and conducts NHIS surveys to find information on hearing ability as an aspect of personal health and societal functioning. With the information the Health Department can assess public health programs and services and determine allocation of resources (Reis, 1994; Benson & Marano, 1995; Adams & Marano, 1995; Blackwell, Collins, & Coles, 2002).

The US Department of Education has several responsibilities for monitoring the participation, services, and programs in education institutions by individuals with deafness. One responsibility is to monitor postsecondary education of deaf and hard of hearing individuals. The Education Department needs information on participation, services, and programs in postsecondary education and on financial support for deaf and hard of hearing postsecondary students. It conducted the Survey on Deaf and Hard of Hearing Students in Postsecondary Education to study of deaf and hard of hearing students who attend postsecondary institutions other than Gallaudet University and National Technical Institute for the Deaf, which are two federally funded national collegiate programs for deaf and hard of hearing students (Lewis & Ferris, 1994). With this information the Education Department can determine the types of postsecondary institutions other than these two federally funded national programs, the number of deaf and hard of hearing students enrolled at these institutions and the extent of the support services provided to these students by the institutions.

The Education Department also has the responsibility to provide financial assistance to postsecondary students who attend college. It needs information on how undergraduate, graduate and first-professional deaf and hard of hearing students and their families pay for postsecondary education and the demographic and other characteristics of those enrolled (Horn & Berkold, 1999). It conducted several surveys. The National Postsecondary Student Aid Study (NPSAS) is a comprehensive nationwide survey of postsecondary students including those with deafness. Starting in 1990 there are two longitudinal surveys the follow the NPSAS survey. The Beginning Postsecondary Students (BPS) Longitudinal Study and the Baccalaureate and Beyond (B&B) Longitudinal Study are follow-ups of alternate NPSAS surveys. The Education Department needs the NPSAS and the BPS surveys to examine the effects of financial aid on entry into, persistence and progress through and completion of graduate-level education (Horn & Berkold, 1999). The Education Department also needs the B&B surveys to examine the relationship between enrollment and progress, degree and employment, and demographic characteristics and enrollment patterns, progress and completion of postsecondary students with deafness (Horn & Berkold, 1999).

One of the surveys conducted by NCES that has information on deafness and hearing impairment is the National Education Longitudinal Study (NELS) (Rossi, Herting, & Wolman, 1997). The information showed up in its 1988 survey (NELS: 88) but was consolidated with blindness and visual impairments into a combined category of sensory impairments in its 1994 survey (NELS: 88/94) (Rossi, Herting, & Wolman, 1997). It is for this reason that the NELS is excluded from this study of post-1990 surveys.

Congress requires that US states provide educational services for children with disabilities, including deafness, in order to encourage their employment, self-help and participation in labor force. Congress also provides funding to state education departments. In IDEA Congress gave the Education Department the responsibility to monitor special education services for students with deafness. The Education Department conducts the Count Counts surveys and collects information on the number of children with deafness receiving IEP services from state education departments. It needs the surveys to help them formulate public education policy, determine funding to state education departments and evaluate the effectiveness of educational programs for children with deafness within states (Office of Special Education Programs, 2001). The Education Department also needs information on special schools and programs for children with deafness and the demographic characteristics of such children regardless of whether or not they receive IEP services. The Gallaudet University's Graduate Research Institute is contracted by the Education Department's Office of Special Education Programs to conduct the Annual Surveys and gather information on the schools and programs for children with deafness and the educational, health, audiological and communication characteristics of such children. It needs the information to help them assess the number, distribution and characteristics of programs and its deaf and hard of hearing students (Holden-Pitt & Diaz, 1998).

#### *Survey questions and population cohorts*

The different juxtapositions of deafness and society reflected in the agendas of the surveying institutions that generated different needs and purposes also framed the survey questions differently. The purposes of the surveying institutions are translated into survey questions. The survey questions are then labeled into population cohorts. Consequently, the different needs and purposes have generated different questions across surveys, which in turn have generated different population cohorts. The purpose of the CRS survey, which is assess the use of hearing for normal conversations, generated questions on whether deafness affected the ability to hear normal conversations. The CRS questions were based on the questions in the 1990 Census. The Census questions were: *Do you have difficulty*

*hearing what is said in normal conversation*, and *Are you unable to hear what is said in normal conversation* (US Census Bureau, 1997). From these questions population cohorts were created. As Table 1 shows, the cohorts were persons who have *difficulty in hearing what is said in normal conversation* and persons who were *unable to hear what is said in normal conversation* (US Census Bureau, 1997). The 2000 Census included a question on hearing impairment in conjunction with visual impairment. Figures are provided but for the number of individuals with sensory impairment (Waldrop & Stern, 2003). It is difficult to sort out the estimates for individuals with deafness based on the Census 2000 data.

The purpose of the SIPP surveys, which is to assess the relationship between hearing abilities and employment of deaf people, was translated to survey questions. In the 1991-1992 SIPP survey the questions asked were whether deaf individuals have difficulty hearing or are unable to hear. In the 1994-1995 and 1996-1997 SIPP surveys the questions that were asked pertained to whether deaf individuals have hearing difficulties and whether the difficulties are severe or not. In all SIPP surveys the questions on hearing acuity were then followed up with questions on employment. The survey questions in questionnaires and follow-up interviews were translated into cohorts. The SIPP estimates of the American deaf population were for those individuals who have *hearing difficulties* and who have *hearing inability* for the 1991-1992 survey and those who have *difficulty hearing* who have *not severe difficulty hearing* for the 1994-1995, 1996-1997 and 2001-2002 surveys.

The purpose of the NHIS surveys, which is to gather information on hearing ability as an aspect of personal health and societal functioning, was translated into interview questions, which were about whether individuals could hear and understand normal voice, hear and understand voice when whispered and when shouted and distinguish speech from other sounds and noises. The questions were derived from the Gallaudet Hearing Scale (GHS), which measures the extent to which an individual has difficulty hearing and understanding normal and whispered speech. From the interviews they created population cohorts. In its 1991 survey the NHIS counted persons as having *hearing impairments* when interviews revealed that they *can hear and understand speech only when shouted*. They also counted persons as having *deafness* when interviews showed that they *cannot distinguish speech from other sounds and noises* (Reis, 1994). In its 1993-2003 surveys the NHIS altered the questions. It became: *Which statement best describes your hearing without a hearing aid: good, a little trouble hearing, a lot trouble hearing, or deaf?* (Lucas, Schiller, & Benson, 2004). For its 1993-1996 surveys the NHIS counted and classified individuals into two cohorts, one was for those who have *a little trouble hearing* and the other for those who have *a lot of trouble hearing or deaf* (Benson & Marano, 1995; Adams & Marano, 1995; Blackwell, Collins, & Coles, 2002; Lucas, Schiller, & Benson, 2004). In the 2003, 2004 and 2006 surveys NHIS combined cohorts who have *a little trouble hearing*, *a lot of trouble hearing*, or *deaf* into one category, entitled *hearing trouble*.

The NCES's NPSAS, BPS and B&B surveys deal with the relationship between deafness, enrollment, finances and postsecondary education. However, each of the NCES surveys slightly differs in the types of students and questions asked of the students. The NPSAS surveys covered undergraduate and graduate-first professional students with deafness while the BPS and B&B surveys covered students with deafness in postsecondary education institutions. In the NPSAS surveys the interview question was: *Do you have any disabilities, such as hearing, speech, or mobility impairment, or vision problems that can't be corrected with glasses?* The questions asked in the BPS and B&B surveys were similar: *Do you have any of the following disabilities (hard of hearing or deafness)?* However, the population cohorts created in the NPSAS, B&B and BPS surveys were not similar. The NPSAS categorized deaf and hard of hearing as *hearing disability* and the B&B categorized it as *hearing impaired or deaf*. The BPS categorized it as *hearing impairment or deaf* in its 1989-1990 survey and *hearing impaired postsecondary students* in its 1993-1994 and 1995-1996 surveys (Horn & Berkold, 1999). The interview questions were changed in the NPSAS and BPS surveys of 2003-2004 to *Do you need the services of sign language or oral interpreters?* The population cohorts were changed in accordance to the changed question to *Service needed: sign language or oral interpreters*. This was done to create consistency in survey questions for the NPSAS and the BPS surveys. In spite of similar survey questions, the population cohorts for the BPS and NPSAS surveys of 2003-2004 differed. The BPS remained focused on institutions of higher education, and the NPSAS remained focused on undergraduate, graduate and professional students.

The Survey on Deaf and Hard of Hearing Students in Postsecondary Education focuses on deaf and hard of hearing students in postsecondary education. Educational institutions were asked whether they

have enrolled any students in the academic years from 1989-1990 to 1992-1994 who identified themselves to the institutions as *deaf* or *hard of hearing* (Lewis & Farris, 1994). The institutions were not provided with definitions of *deaf* and *hard of hearing* for counting purposes. Lewis and Ferris (1994) contained definitions of deafness that were borrowed from Research and Training Center on Independent Living (1993). *Hearing impairments* is a generic form used to indicate any degree of hearing loss, from mild to profound, and includes both deaf and hard of hearing. *Deaf* is a profound degree of hearing loss that prevents the reception of speech through the ear. *Hard of hearing* refers to a mild to moderate hearing loss that may or may not be improved through amplification (Lewis & Farris, 1994). These categories became the cohorts in the surveys from 1989 to 1994.

The Child Counts deal with deaf and hard of hearing children who receive IEP services. It utilizes IDEA classifications for deafness. IDEA provides two classifications for deafness, which are *deaf* and *hard of hearing*. *Deaf* is a severe hearing impairment that prevents a child from processing linguistic information through the use of audition. *Hard of hearing* is a hearing impairment that is not included under the definition for *deaf* but that also affects a child's educational performance. In the Child Counts both IDEA constructions are consolidated into *children with hearing impairments* who require IEP services. State education authorities counted children who are classified as having hearing impairments if they are diagnosed as such and if they receive IEP services. The estimates for the American deaf child population in the Child Counts were for *children with hearing impairments* who receive IEP services.

The purpose of the Annual Surveys of Deaf and Hard of Hearing Children, which is to study the characteristics and enrollment patterns of students who attend special schools and programs for the deaf and the hard of hearing in the US, generated questions on hearing and communication abilities, types of educational programs and some other questions on student characteristics. It used the Gallaudet Hearing Scale and types of educational settings as demographic variables. The types of educational settings ranged from special schools to integrated classrooms. The degrees of deafness and types of educational programs and services were the bases for the construction of deaf population cohorts. In the 1989-1990, 1991-1992, and 1993-1994 Annual Surveys the estimates were for *hearing impaired children and youth who received primary or secondary special educational services in local public schools or in special residential or day schools for the deaf* (Schildroth & Hotto, 1991, 1993, 1996). The estimates for the 1994-1995 Annual Survey were for *all deaf and hard-of-hearing children receiving special educational services in the US*. The 1997 estimates were for *all deaf and hard-of-hearing children who attended any US program or school, both public and private and deaf children who received special education services*. In the 1999-2000 to 2006-2007 Annual Surveys only those *children who received special education services* were counted (Gallaudet Research Institute, 2001). The conceptualizations of the deaf child population cohorts seem to vary slightly over the years of the surveys.

#### *Survey methodologies and respondents*

The survey questions and resultant cohorts that were framed by survey purposes also determine certain types of respondents. Different surveying institutions devised different methodologies for reaching and counting individuals with deafness. Different surveys were sent to different respondents. In addition, some surveys relied on self-reported data, some used questionnaires on functional hearing of conversations, some used audiometric data and some others used institutional data.

The CRS surveys were initiated by responses to questions on hearing in the decennial Census. The CRS mailed questionnaires and conducted interviews with individuals aged 16 and over who affirmatively responded to the Census questions in the long form on hearing difficulties. The SIPP surveys were mailed out to regionally based samples of households and individuals aged 15 years and over. Individuals were asked about their hearing abilities, identified and interviewed. The NHIS surveys were also mailed out to with randomly selected 40,000 households in the civilian noninstitutionalized population. They contained questions on deafness in the family. Individuals who responded in the affirmative were first identified and then interviewed by the NHIS.

The NPSAS survey questionnaires that included questions on deafness and hearing impairments were mailed to postsecondary students. Those who reported their hearing disability were followed up with computer-assisted telephone interviews. For the BPS survey students included in the NPSAS who had just started their postsecondary education were contacted and interviewed two additional times throughout their education and employment. For the B&B survey the NPSAS students were also

contacted one year after the NPSAS surveys and given interviews. For the Survey on Deaf and Hard of Hearing Students in Postsecondary Education survey coordinators were assigned to institutions. They were asked whether their institutions had enrolled any students who self-reported as deaf, hard of hearing or a combined category of hearing impairment. The OSEP sent Child Counts questionnaires to authorities at state education departments. The state education authorities responded to survey questions and counted children within their states who were deaf and received IEP services. The GRI mailed out questionnaires for the Annual Surveys of Deaf and Hard of Hearing Children to administrators of special schools and programs for deaf and hard of hearing children. School administrators filled in the number of children within their schools and programs.

#### *Survey coverage*

The survey questions, population cohorts and methodologies constrained the surveying institutions to cover certain individuals. The CRS identified individuals who responded in the Census that they have hearing difficulties. The SIPP and the NHIS counted individuals who responded in the affirmative to survey questionnaires and interviews that they have hearing difficulties. The Survey on Deaf and Hard of Hearing Students in Postsecondary Education counted individuals who reported to their institutions that they are deaf or hard of hearing. The NCES surveys identified students who self-reported that they have hearing disabilities for the earlier surveys and need interpreters for the later surveys of NPSAS and its longitudinal follow-up surveys, the BPS and B&B. The Child Counts counted children who received IEP services. The Annual Surveys counted children who attended schools and programs for the deaf and the hard of hearing.

In addition, each survey covered different age groups within the deaf population. The 1990 CRS covered individuals aged 16 and over. The NHIS covered adult population aged 18 and over. This age range is the range of ages of persons that the CRS and NHIS considered able to conduct societal activities and live independently (US Census Bureau, 1997). Not on reference (I deleted the 2000 date.) Lethbridge-Cejku & Vickerie, 2005). The CRS did not include persons of other ages and who did not claim that they experience difficulties in hearing normal conversation, even though their audiograms and personal experiences may indicate otherwise. The SIPP data were also limited to a small sample size of the deaf population. The SIPP provided separate demographic figures for two age groups, ages six to 14 and ages 15 and over. Why the SIPP included the age range of six-to-14 year old was not explained in its surveys. Individuals from this age group are not eligible for employment, as per federal regulations on child labor. Furthermore, the surveys were limited to a sample of deaf civilian noninstitutionalized population. The institutionalized deaf civilian population and deaf people in the military were excluded from the surveys. The Child Counts and the Annual Surveys covered school-age children, not adults. The former covered children receiving IEP services and the latter covered children six-17 year olds who attend special schools and programs for the deaf and the hard of hearing. Since 2000 they added figures for children three to five years old, but the figures are not shown in the table here. The three NCES surveys covered adults in postsecondary education. It has been reported that the age ranged from below 18 to over 40 years (Horn & Berkold, 1999). There is no information on the age range of students in the Survey on Deaf and Hard of Hearing Students in Postsecondary Education. Because surveys differ in the age ranges of its respondents, population estimates across surveys may not cover the same age ranges, and it is not possible to compare population estimates across the surveys.

#### **Discussion**

Surveys do not agree with each other on estimates of the deaf and hard of hearing population. Previous studies on the demography of deaf and hard of hearing population examined the discrepancies in estimates across surveys. They explained the discrepancies in terms of sampling and probability errors, different survey methodologies, federal mandates, changing medical conditions and fluctuations in prevalence rates. The problem with previous studies is that demographers assume that different surveys cover the same set of deaf and hard of hearing populations and carry similar definitions and characteristics of people with deafness. However, the role of different surveying institutions with its own agendas and purposes need to be explored as possibly shaping the different estimates of deaf and hard of hearing population. This study takes a critical demography model and finds that estimates are results of the purposes and agendas of surveying institutions. It shows that different surveys produce different estimates because of different mandates and agendas, which have impacted on the shaping of questions, methodologies and types of respondents.

Different surveying institutions produced different estimates of the American deaf population since 1990. While all demography studies are mandated and funded by the US Congress, Congress funds

different survey projects of competing constellations of federal surveying agencies and public and private program and service agencies. The constellations revolve around the US Department of Commerce, the US Department of Health and Human Services, and the US Department of Education. Each institution has different purposes for conducting demography studies, and definitions of population cohorts. The US Department of Commerce is interested in the economic situation of the American deaf population, the US Department of Health and Human Services focuses on the health situation of the deaf population, and the US Department of Education deals with the education situation of the population. The impetus for their different purposes is based on their different needs for conducting the surveys. The US Department of Commerce need people count to assess the labor force, self-help, and participation of the deaf population in its labor and welfare programs. The US Department of Health and Human Services need surveys to examine the health conditions of the deaf population and its participation in its self-help and well-being programs. The US Department of Education requires surveys to study the implementation of federal education laws and the effectiveness of special education services for the deaf child population. The different needs and purposes of the surveying institutions suggest that they, in counting deaf people, focus on certain aspects of deafness that are integral to their missions. The surveys do not speak about the same set of deaf people. They focus on different subsets of the American deaf population. The Commerce Department deals with the employability of deaf people, the Health and Human Services Department deals with the general well being of deaf people, and the Education Department works with the educability of deaf people. Their focus on certain aspects of deaf people to the exclusion of others underlies the problems of demography.

Demography is a problematic field because it is an extension of social policy. Social policy is reflected in the political, social, and economic motivations of the demography institutions regarding persons with deafness. The motivations are nested in their agendas and purposes. Social policy requires demography to assess needs, agendas and programs. The divergences in estimates across surveys suggest that demography is an extension of social policy. Demography is a politico-economic activity conducted by organizations and institutions in order to assess and justify their funding, programs and services, and personnel management. As the above discussion of tables shows, social policy may have skewed population figures. What is clear from the foregoing is that one needs to take caution when examining and using demography data on the American deaf population. One needs to be mindful that the estimates are a function of the agendas and mandates of the surveying institutions that conduct the surveys.

Accurate estimates of the deaf population are essential for studying deaf people and the different aims of surveys and incompatibilities of definitions across surveys hinder valid research, meaningful projections of program needs and clear communication between professionals. Confusions in research and educational practices and the eligibility and ineligibility of deaf people from programs and services are but unfortunate consequences of demography as a sociopolitical act (see also Bienenstock & Vernon, 1994). The survey questions, population cohorts and methodologies may delimit the deaf population. Population estimates may be further affected by conflicting agendas between the respondents and the surveying institutions. These critical issues have the potential to exclude certain groups of deaf individuals from enumeration and skew estimates of the deaf population. The possible effect is that the counting of some individuals to the exclusion of some others may have skewed demography studies and the allocation of resources, programs, and services by the governmental departments and public and private organizations and agencies to the detriment of individuals who get excluded in the surveys. While a discussion of this possibility is outside of the scope of this study, it is worth further investigation.

What is clear is that people count—that is, who gets counted and who does not—is a function of the sociopolitical aims of the surveying institutions and their angularized perspectives of deaf people. Once the angularized perspectives and the sociopolitical aims of the surveying institutions are taken into account, the population estimates can be better analyzed and understood.

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